From the Fall 2003 Newsletter

FROM THE FIELD

Early in the HIV/AIDS epidemic, medical concerns overshadowed ethical issues. But professionals soon learned that caring for AIDS patients required them to be moral as well as clinical leaders.

The Early Years of HIV/AIDS at the New York Campus, VA NYHHS

Michael S. Simberkoff, MD

In the beginning, we called it gay-related immunodeficiency syndrome (GRID). The first patient with GRID appeared on the wards of the New York VA Medical Center (NYVAMC, now the New York campus, VA NYHHS) in 1979. He was a young man with Kaposi's sarcoma (KS) that was widely disseminated on his skin, mucous membranes, and in his lung. He died despite efforts to control the disease with chemotherapy. He was followed by a stream of others, some with unexplained fever, lymphadenopathy and weight loss; some with malignancies (e.g., KS or non-Hodgkins lymphoma); some with opportunistic infections (e.g., *Pneumocystis carinii* pneumonia (PCP), Candida esophagitis, cryptococcal meningitis, cerebral toxoplasmosis, disseminated *Mycobacterium avium-intracellulare complex* (MAC) infection, cryptosporidiosis, progressive multifocal leukoencephalopathy); and some with progressive dementia. By the time that the Centers for Disease Control and Prevention (CDC) had renamed the disease (acquired immunodeficiency syndrome: AIDS), established its etiology (human immunodeficiency virus, type 1: HIV-1), and determined its principle means of transmission, we at NYVAMC had learned to deal with most of its clinical manifestations.

Many of our early AIDS patients came to the hospital in a near terminal condition. Tragically, most of these patients died. However, some survived, and soon we realized that they needed ambulatory care. We opened an infectious diseases (ID) clinic in 1983. My colleagues, James J. Rahal, Jr., MD, then the Chief, ID Section, and Wafaa El-Sadr, MD, myself, and our ID fellows decided that the ID staff would provide both continuity and comprehensive primary care to the patients who came to our clinic. We were aided by a superb immunology laboratory directed by Susan Zolla-Pazner, PhD. From a scant few ambulatory patients in 1983, our clinic rapidly expanded to accommodate approximately 1,000 unique patients every year, and to provide sessions three times weekly so that our patients could almost always find their own primary care provider and/or a faculty member who knew them well.

The leadership of our facility and VA Central Office supported improving services for HIV-infected patients from the beginning. A ward was renovated at our facility both to care for those who required hospitalization and to provide a day hospital for ambulatory patients requiring aerosolized pentamidine or intravenous amphotericin B treatments. Housestaff welcomed the special training that they

received from the ID faculty that supervised care on the ward. A volunteer nursing staff (led by Cynthia Coke, RN) and social work staff (led by Lloyd Moore, MSW and Maggie McGibbon, MSW) provided special care for the patients.

Treatment of GRID/AIDS patients was never an issue for the ID and most of the other medical and nursing staff at the NYVAMC. However, there were problems. Early in the epidemic we discovered several instances in which meal trays were not delivered into the rooms of AIDS patients, rooms were not cleaned, or essential procedures were delayed. We were fortunate to have an excellent infection control team led by Ronnie Leibowitz, RN and Debbie Hirsch-Temple, RN. They educated and re-educated our staff and eventually helped to overcome fear and eliminate irrational behavior. In addition, Frank Spencer, MD, then Chairman, Department of Surgery, NYU School of Medicine and a pioneer in cardiovascular surgery, made a point of agreeing to personally do an aortic valve replacement in a patient with KS. This effectively ended our difficulties in obtaining necessary surgical consultation and treatment for patients.

By the mid-1980s, it was apparent that the HIV/AIDS epidemic was a national problem that would not soon go away. It also was obvious that many VHA facilities were treating large numbers of AIDS patients. I met with Ira Tager, M.D. of the San Francisco VAMC and developed a plan for a computerized database detailing entry and follow-up on all AIDS patients treated within VHA. This was presented to VA Society for Practitioners of Infectious Diseases (VASPID) colleagues at the annual Infectious Diseases Society of America (IDSA) meeting in New York City in 1986. Although the plan was not immediately endorsed, it did lead VACO to develop and implement a system for extracting both administrative and clinical data from VHA's VistA database, the immunology case registry (ICR).

During the same period, it also became obvious that treatment of HIV would be necessary to control the disease in individual patients and the growing epidemic it was causing in the United States. I teamed with John Hamilton, MD, Chief, Infectious Diseases at the Durham, North Carolina VAMC, and Pamela Hartigan, PhD, at the CSPCC, West Haven, Connecticut to design and carry out CSP #298, a trial comparing early versus late treatment with zidovudine in HIV-infected patients. This trial ultimately involved patients from the ID clinics of the New York, Miami, Houston, West Los Angeles, and San Francisco VAMCs. It was the beginning of the anti-retroviral era.